Isle of Wight Pain Clinic
Patient information leaflet

Complex Regional Pain Syndrome (CRPS)

Other names used: algodystrophy, causalgia, algoneurodystrophy, reflex sympathetic dystrophy, Sudeck's atrophy, shoulder-hand syndrome, reflex neurovascular dystrophy, fracture disease

**What is CRPS?**

CRPS is characterised by unusually intense and prolonged pain and/or hypersensitivity in a body region/limb, most often (but not always) following an injury or operation. It can happen in as much as 10-30% of bone fractures, and up to 15% of nerve injuries.

CRPS symptoms are described as

- Pain of burning character
- Reduced range of movement of the affect joint or limb
- Unpleasant sensation or pain to light touch (e.g. clothes) called *allodynia*
- Prolonged or recurring swelling (oedema)
- Spontaneous changes in skin temperature or colour compared to the other body side (white or blue and cold, red and hot)
- Changes in local sweating (increased or reduced) and/or local hair growth
- Local thinning of skin, muscle and bone (wasting, atrophy, local osteoporosis)
- Muscle spasms and shortening of tendons can sometimes lead to deformities or spasticity in the longer term

Sometimes, these changes can gradually spread to a wider area or affect the other side (mirror symptoms).

**What is causing it?**

Despite ongoing research it is still not clear what exactly causes and maintains these changes. Several factors such as disturbed autonomous nerve function (controlled blood flow and sweating), inflammatory changes, local and central (brain and spinal cord) sensitisation of nerve cells seem to play an important role. Long term reduced blood flow and underuse of muscles can lead to wasting, atrophy with shortening of muscles or ligaments as well as osteoporosis as indirect consequences.

**How is it diagnosed?**

There is no test or scan to diagnose CRPS. The diagnosis is usually made based on the presence of typical symptoms and by exclusion of treatable causes (e.g. non-union of a fracture, infection, haematoma, thrombosis etc). This is usually done by the specialty referring you to the Pain Clinic (e.g. Orthopaedics or General Surgery) and is confirmed by a Pain Specialist.
What are the treatment options?
There is no permanent cure currently available for CRPS. Different forms of treatment working
 together aim to reduce pain and hypersensitivity and improve function and movement. The sooner
treatments start the better their chance of effect and success. Options include

- **Specialized Physiotherapy including techniques such as mirror therapy**
- **Medicines such as tablets or external creams or skin patches or infusions**
  Various medicines in form or tablets, creams, patches and infusions can help. These include
  standard pain killers as well as specific medicines to control inflammation, nerve cell
  sensitivity, muscle tone and bone turnover. Response to these medicines is individual, so it is
  often necessary to try a few to find the best combination for you, optimizing relief and
  minimizing side effects. In most cases several different medicines are necessary to achieve a
  good effect.

  *Please note that these medicines are not licensed or not licensed for this treatment in the UK. Not all medicines are available locally.*

- **Injections**
  - Targeted nerve injections remote from the painful region (e.g. sympathetic nerve blocks)
  - Injection/infusion into blood vessels of the affected limb (Guanethidine block)
- **Psychological treatments**
  - For pain-associated problems with emotions and frustration/distress
  - If coping and self management remain unsatisfactory
- **Spinal Cord stimulation**
  - A bit like an internal/implanted TENS machine
  - Internal wired electrodes on spinal cord nerves to relief pain and hypersensitivity

  *Not available locally, and needs funding agreement from commissioners.*

- **Surgical removal of specific autonomous nerves (sympathectomy)**
  - Maybe useful if targeted injections provided good but short-lived relief only.
  - Can have long-term consequences from removed/missing autonomous nerves

  *Not available locally, and needs funding agreement from commissioners.*

What is the longer-term outlook?
- CRPS can be hard to treat and control. A full removal of symptoms is often not possible. The
  sooner treatment starts the better the long-term outcomes. It is ideal to start a combination
of treatments within 6 months of onset of symptoms, but later treatments can also work. The longer the symptoms have been around, the lower the chance of full restoration of function. Treatments aim at controlling pain and sensitivity as well as function/movement and prevent long-term consequences such as atrophy, dystonia and contractions.

- A realistic acceptance of ongoing symptoms to one extent or other, and adjustments of activities of daily life, possibly including work with the affected limb is usually necessary.
- There is a good chance that pain, sensitivity and other symptoms will improve over time. Ca. 85% of patients with CRPS improve noticeably within 2 years of onset of symptoms.

What should I do to help myself?

- Be patient with yourself and develop a realistic acceptance of some of your symptoms while engaging with the pain clinic team to get better.
- High levels of frustration, anxiety and emotions are understandable and a frequent problem! If these are barriers to progress or get out of hand they should be actively addressed early on e.g. via psychological treatment, which is often necessary.
- Take medicines regularly and consequently during trial periods. Some treatments - particularly medicines – can take several weeks to fully work. If, however, there is no or only minor effect after the agreed trial period, the treatment should be discontinued and the next treatment option be pursued without undue delay.
- Continue to use and exercise your limb within tolerable limits to avoid atrophy and contractions. Regular exercises are important to maintain and improve mobility, and you should receive instructions from a suitably experienced physiotherapist what to do, at what intensity level and how frequently.
Advice on exercises and activity

*These are taken from the UK guidelines for Complex Regional Pain Syndrome in Adults, Royal College of Physicians, 2012*

**Regular practice: little and often**
Regular practice of these activities will increase the benefit. A short period of desensitisation (even 1–2 minutes) as many times as possible throughout the day is recommended. It might be helpful to set aside particular times during the day to perform them. A quiet, relaxed environment with few distractions will help you to concentrate on the task.
As you progress you may find other activities within your daily routine in which to incorporate these principles.

**Discomfort**
It is usual for these activities to be uncomfortable and somewhat painful whilst doing them and shortly afterwards. You may find that there are certain activities that you are unable to tolerate. Choose one that you feel comfortable with and gradually progress to others as you are able to do so. If you experience intolerable pain and discomfort, then stop that activity and find one that is more tolerable.

**Concentration is important**
To help normalise the system, it is important that you concentrate on the quality of the sensation. This can be done by first undertaking the activity on a limb unaffected by CRPS. Concentrate on how this sensation feels, remember it and then undertake the activity on the affected area, whilst looking at it and thinking about it.

**Suggested activities**

**1) Activities of daily living**
Desensitisation therapy can be incorporated into activities of daily living as part of your normal routine.

**Whilst in bed**
Feel the bed sheet against your unaffected limb. Close your eyes and concentrate on the quality of that sensation. Now feel the bed sheet against your affected area and recall how that normal sensation felt whilst thinking about the area you are touching.

**Whilst dressing**
Concentrate on your affected limb by looking at it and thinking about it as you get dressed. Feel the texture of the garment against your skin both on the unaffected and the affected areas.

**Whilst having a bath or shower**
Select a water temperature that you can tolerate. Feel the water on your unaffected body and now on your affected limb whilst looking at it and thinking about it. Recall how that normal sensation of the water felt against your skin.
Gently rub either a soft flannel, sponge or ‘scrunchy’ on the unaffected areas of your body. Use various movements such as circular actions, rubbing, patting and stroking. Concentrate on how these normal sensations felt whilst applying the movements to the affected areas of your body.

Activities for the upper limb only:

**Whilst washing up**
Feel the temperature of the water on both the affected and unaffected areas of your hands. Think about how the normal sensation of the water feels whilst concentrating on your affected hand. Focus on the action of your affected hand in the water. Where tolerable, use different water temperatures such as tepid, hot and cold. Immerse your unaffected hand first, then your affected hand for short periods. These periods can be lengthened over time.

**Whilst cooking**
When you are making pastry or bread, mix it with both hands. Concentrate on the texture of the mixture and action as you are doing so.

2) Use of different textures

- Applying different textures to the skin is another way to re-educate the sensory system.
- Gather a variety of rough and smooth textures that you can tolerate. Here are some suggestions:
  - Smooth – Felt, satin, silk, velvet, make-up or soft paint brushes
  - Rough – towelling, netting, scourers, flannel, wool, hook velcro.
Place them on your unaffected limb and apply movements such as light stroking, firm stroking, tapping and circular actions. Note the various normal sensations that you feel. Now on the affected limb, apply the texture in similar movements working from an area that you can tolerate towards the more uncomfortable skin areas for example from the top of the arm towards the hand. Concentrate on the area by looking at it and thinking about it. Recall the normal sensations that you felt on the unaffected limb.

3) Massage
Massaging the affected limb can also be beneficial. This can be done by either yourself or someone else. Moisturisers or massage oils can be used. Be sure not to use anything which may irritate the skin. Use different pressures such as soft touch and firm massage where tolerable. Apply various movements such as patting, stroking and circular actions. Concentrate on the area being touched by looking at and thinking about it. Massage from your fingers and toes towards the centre of your body.

Further information online:

- [www.nhs.uk](http://www.nhs.uk/Conditions/Complex-Regional-Pain-Syndrome/Pages/Introduction.aspx)
- [www.arthritisresearch.uk](http://www.arthritisresearch.uk/~/media/Files/Arthritis-Information/Conditions/2035-Complex-regional-pain-syndrome.ashx&sa=U&ei=b901UauQEcZG9GFJFqGg&ved=0CCkQFjAD&usg=AFQjCNGM3UJokxOOGGm7dQcDJdd2K74bA)
- [www.mayoclinic.com](http://www.mayoclinic.com/health/complex-regional-pain-syndrome/DS00265)
- [Royal National Hospital for Rheumatic diseases](http://staff.bath.ac.uk/psskr/patient%20leaflet%20version%201.pdf)
- [Regional Sympathetic Dystrophy Syndrome Association](http://www.rads.org/aboutCRPS.html)